Title  A Systematic Review of Presumed Consent Systems for Deceased Organ Donation

Agency  NETSCC, HTA, NIHR Evaluation and Trials Coordinating Centre
Alpha House, University of Southampton Science Park, Southampton, SO16 7NS, United Kingdom; Tel: +44 2380 595 586, Fax: +44 2380 595 639; hta@soton.ac.uk, www.hta.ac.uk

Reference  Volume 13.26, ISSN 1366-5278. www.hta.ac.uk/project/1735.asp

Aim
To examine the impact of presumed consent legislation on organ donation and to review data on attitudes to presumed consent among the public, professionals, and other stakeholders.

Conclusions and results
Presumed consent alone is unlikely to explain the variation in organ donation rates between countries. A combination of legislation, availability of donors, transplantation system organization and infrastructure, wealth and investment in health care, and underlying public attitudes to and awareness of organ donation and transplantation, may all play a role (but the relative importance of each is unclear). Further reviews could investigate the factors likely to modify donor rates, eg, procedures for family involvement. The way in which families of a potential donor are approached is likely to be important, and a review of qualitative research examining the experience of relatives in this context would be useful. Over 2000 potentially relevant citations were identified, of which 13 studies met the inclusion criteria for the primary objective and 13 for the secondary objective. For the primary objective, 8 studies were between-country comparisons and 5 were before-and-after studies. Four of the between-country comparisons were of sufficient methodological quality to provide reliable results. In all 4 studies presumed consent law or practice was associated with increased rates of organ donation, ranging from an increase of 2.7 donors per million population (pmp) in one study to 6.14 donors per million in another, and an increase of between 20% and 30% in 2 other studies. Factors other than presumed consent that had an impact on organ donation rates were: mortality from road traffic accidents and cerebrovascular accident, the transplant capacity of a country, GDP per capita and health expenditure per capita, religion, education, public access to information, and a common law legal system. The 5 before-and-after studies represented 3 countries, all of which reported an increase in donation rates following the introduction of a presumed consent system. There was limited investigation of other changes taking place concurrently with the changes in legislation across this set of studies. Of the 13 studies addressing the secondary objective, 8 were surveys of the UK public, 4 were from other countries and 1 was an international survey of health professionals. The UK surveys varied in the level of support for presumed consent, with surveys conducted before 2000 reporting the lowest levels of support (28%-57%). The most recent survey by YouGov in 2007 reported that 64% of respondents supported a change to presumed consent.

Recommendations
See Executive Summary link at www.hta.ac.uk/project/1735.asp.

Methods
See Executive Summary link at www.hta.ac.uk/project/1735.asp.

Further research/reviews required
When a change in legislation occurs it is important to evaluate and monitor the impact on donor rates and other factors, eg, registration to opt out. Further reviews could investigate the factors likely to modify donor rates, eg, procedures for family involvement. The information obtained could be used to determine a priori the factors to be investigated in any evaluation of a change in legislation. Concurrently, contextual information should be gathered, eg, transplant capacity and any ongoing media campaigns. As public views about presumed consent are crucial, future surveys should carefully consider the framing of questions and be designed to minimize the strong possibility of providing what is viewed as a socially acceptable answer.

Written by Dr Amanda Sowden, NETSCC, United Kingdom

ISSN 1654-501X